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ABSTRACT

In 2002, the Bazelon Center for Mental Health Law investigated the impact of expanding child mental health services in Medicaid on the actual availability of services to children. To assess family satisfaction, focus groups were held in two states: Oregon and New York. Both states have a comprehensive Medicaid mental health benefit for children with serious disorders. Oregon employs a managed care system, while New York uses a fee-for-service approach to deliver these services. This report summarizes findings from the three Oregon focus groups. Parents generally found services covered under the Oregon Health Plan to be helpful to their children--when they were able to obtain them. Generally, children of all ages have access to some level of basic outpatient treatment, particularly medication and limited psychotherapy. However, parents reported significant problems accessing more intensive community rehabilitation needed by children with serious emotional disturbances. While the state places an emphasis on early intervention for very young children, most children on the Oregon Health Plan do not benefit from early recognition of their disorder. Despite the state Medicaid plan's comprehensive child mental health services benefit, children are too often unable to access many of these services when they need them. The findings from these focus groups have important ramifications for child mental health policy in Oregon. Parents believe that substantial improvements are needed in the state system for providing services to children with mental disorders. Two appendixes contain the focus group methodology and data tables. (GCP)

ASSESSING CHILD MENTAL HEALTH SERVICES IN THE OREGON HEALTH PLAN

A REPORT ON THREE FOCUS GROUPS

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Fall 2002

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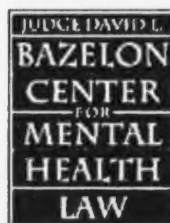
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The Bazelon Center for Mental Health Law is the leading national legal advocate for people with mental disabilities. Since its founding in 1972, the nonprofit organization's precedent-setting litigation and public-policy advocacy has successfully challenged many barriers and expanded access to public schools, workplaces, housing and many other opportunities for community life. Today we work to end the punishment of children and adults for the failures of neglectful public mental health systems and to achieve full membership in the community for all people with mental disabilities.

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EXECUTIVE SUMMARY

Over the past decade, the effectiveness of services for children with serious mental disorders has improved significantly. Today, an array of evidence-based interventions can be provided in the community, enabling many children to live at home. Recognizing the need to cover these services, states have adjusted their Medicaid programs accordingly. Because of these changes, a broad array of children's services in public mental health systems are now covered by Medicaid's rehabilitation services category.¹ Children on Medicaid are entitled to any necessary health service covered by federal law. These services are detailed in each state's Medicaid plan. However, listing services in a state's plan is only the first step. Whether children can access these services depends on actual service availability in individual communities.

In 2002, the Bazelon Center for Mental Health Law, with funding from the W.T. Grant

Foundation, investigated the impact of expanding child mental health services in Medicaid on the actual availability of services to children. To assess family satisfaction, focus groups were held in two states: Oregon and New York. Both states have a comprehensive Medicaid mental health benefit for children with serious disorders. Oregon employs a managed care system, while New York uses a fee-for-service approach to deliver these services. This report summarizes findings from the three Oregon focus groups.

Parents generally found services covered under the Oregon Health Plan to be helpful to their children — when they were able to obtain them. Generally, children of all ages have access to some level of basic outpatient treatment, particularly medication and limited

psychotherapy. However, parents reported significant problems accessing more intensive community rehabilitation needed by children with serious emotional disturbances. With few available services to help teens develop the skills for independent living, parents found the serious shortage of appropriate services for adolescents to be particularly problematic.

While the state places an emphasis on early intervention for very young children, most children on the Oregon Health Plan do not benefit from early recognition of their disorder. Parents instead were often blamed for their child's problems and their insights into the seriousness of their children's disorders were

often ignored. Many parents waited years for recognition of problems they had noted and sought assistance for when their child was very young, often in infancy. Even after problems are recognized, there are often long wait lists for services

and parents continue to struggle with the perception that they are to blame for their child's problems.

Children deteriorate as families struggle to cope without adequate guidance or backup. The lack of early identification, the scarcity of information available to parents regarding service options and the minimal provision of limited outpatient treatment — even for children with very serious disorders — result in a crisis-oriented system. These children require a range of services, targeted to their individual needs. In-home services, day treatment and case management are all covered under the Oregon Health Plan, but apparently few children receive them.

"I'm trying to tell them now that children don't normally bite themselves and pull their own hair out. And my daughter's doing this and no one will listen. She's four. And nobody will listen." (Jefferson Behavioral Health Care)

Without adequate services, children often go into crisis. Parents generally found Oregon's crisis systems to be extremely inadequate. For many families, all that is available is a hotline that offers little help but directs families to contact the community mental health clinic during normal business hours or to go to a hospital emergency room. Parents reported that often their only option was to call the police.

The lack of information on what services can be covered under the Oregon Health Plan further complicates parental efforts to obtain services for their children. Parents in the focus groups were often unaware of available benefits, having received insufficient information from their plan, the county and the state. As a result, many parents did not know that certain important services needed by their children could be covered.

Without adequate access to outpatient treatment or needed intensive community rehabilitation services, many families are forced into the child welfare or juvenile justice systems in a desperate attempt to get help for their child. Far from providing a solution, this approach often only raised new challenges for families seeking services for their child.

Many parents reported being told by providers that the only way to receive more services—in other words, to become a priority for the system—was to enter into an agreement with child welfare. Such agreements can provide a gateway to services for families whose children need intensive mental health services that the family has no other way to access. Oregon law's provisions on these voluntary agreements are intended to protect families, but many parents reported being pressured into giving up their parental rights in order to get their child services. Those who did get voluntary agreements reported they were nonetheless treated as if they were guilty of abuse or neglect, despite the law's intent.

Other state systems serve children's mental health needs no better. Schools have limited services and do not respond to these children's needs. Juvenile justice is a punitive system, and children who come into that system due to untreated mental disorders do not receive the services they need. Agencies also cost-shift, assuming (or hoping) that someone else will take responsibility for a particular child. As a result, child mental health services are not only woefully inadequate but also extremely fragmented.

Despite the state Medicaid plan's comprehensive child mental health services benefit, children are too often unable to access many of these services when they need them.

The findings from these focus groups have important ramifications for child mental health policy in Oregon. In particular, there is a need for:

- training of staff in mental health, child welfare, education and juvenile justice agencies to better recognize serious mental disorders and to take more seriously the reports of parents;
- significant expansion of access to evidence-based community rehabilitation services known to help prevent children from deteriorating to the point where they need expensive 24-hour care or where parents feel they must turn to child welfare or juvenile justice systems for help;
- addressing the gap in mental health crisis services so that families need not depend on hot lines that provide very little guidance and on hospital emergency rooms that lack sufficient trained staff to handle these children;
- interagency collaboration at state and county levels to create an integrated system of care to replace the state's current fragmented approach where agencies too often work against each other; and

- providing parents the information they should have — a complete and detailed list of the services covered for children in the Oregon Health Plan.

Oregon's experience is, unfortunately, consistent with that of other states struggling to provide children with emotional disturbances access to services through Medicaid. Independent commissions and task forces in many states are increasingly identifying significant problems in public child mental health systems.² Across the country, children's mental health needs are left unmet. The broadening of

Medicaid service options, while encouraging, may mask an opposing trend — reductions, or at least a lack of expansion, in the real availability of services for children with emotional disturbances.

These conditions are not isolated to Oregon, but the fact remains: Oregon's children deserve better. Parents believe — and the Bazelon Center agrees — that substantial improvements are needed in the state system for providing services to children with mental disorders.

INTRODUCTION

Oregon's large size and small population of 3.4 million pose challenges for the delivery of mental health services. Though one of the largest states in terms of area, the number of persons per square mile is less than half the national average.³ Seventy percent of the state's population is concentrated in the three urban areas (Medford-Ashland, Eugene-Springfield, and Portland-Salem). Nearly two million people live in the Portland-Salem metropolitan area⁴ and about a million live in rural and frontier areas. The state's population is less diverse than the country as a whole, with 86.6% being white. Hispanics are the largest minority group representing 8% of the population, followed by Asians at 3%.⁵

The Oregon Health Plan (OHP) operates with a federal waiver that permits enrollment of Medicaid-eligible individuals in managed care plans. It also covers significant numbers of uninsured persons in the state.

Not all of the Medicaid population is enrolled in OHP. To maintain provider continuity or find a provider who accepts Medicaid, families may opt out of managed care and receive services through fee-for-service using the plan's "open card" option.

In 1995, nearly 16% of children aged 0-18 were covered by Oregon's Medicaid program.⁶ Oregon has since expanded coverage through OHP, reducing the number of children without health insurance from 21% to 8%.⁷ Medicaid enrollees have a more expansive benefit package than the near-poor uninsured individuals who are on the plan. The OHP benefits include treatment for mental illnesses as an integral part of the overall benefit package.

The OHP operates through fully capitated health plans (managed care entities) that are responsible for health care and substance abuse services. County and regional Mental Health

Organizations (MHOs) are contracted separately to provide mental health services. County mental health departments have the right of first refusal to bid for the MHO contract. Larger counties, such as Multnomah and Clackamas, have created their own MHOs, while rural counties often join together.

OHP has separate funding mechanisms for certain high-intensity residential and day services. Using direct contracts between the state and the provider that are based on a daily rate, the state pays for:

- extended inpatient care at Oregon State Hospital for children suffering from severe functional impairment;⁸
- therapeutic foster and proctor care, as well as therapeutic group homes, which are community-based alternatives to psychiatric residential and hospital levels of care; and
- residential treatment centers and psychiatric day treatment, referred to as Child/Adolescent Intensive Treatment Services (ITS). The ITS day treatment programs offer placements to children who cannot attend regular school because of mental or emotional disorders.

Oregon's Office of Mental Health & Addiction Services has since 1999 piloted the Kids Intensive Mental Health Treatment and Services (KITS) program. The program merges residential treatment funding with funding for psychiatric day treatment into a single rate that is channeled through the managed care contracts. KITS provides residential and outpatient services to a small number of children with serious mental disorders. In 2000, twenty slots were available in 10 counties.⁹

In recent years, OHP has been adversely affected by low provider rates and the departure

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of private health plans. Many providers have left OHP due to its low payment rates.¹⁰ Several of the fully capitated commercial health plans and a few capitated MHOs have either left the OHP completely, exited selected counties or reduced enrollment. As a result, the percentage of OHP enrollees covered by managed care has fallen from 85% in 1998 to 65% in 2000.¹¹

Several studies confirm the difficulty in accessing mental health services under OHP. A 1998 survey of primary care physicians found that 52% reported that OHP patients referred for mental health services were placed on long waiting lists. Fifty-nine percent did not believe that the plan provided adequate mental health coverage.¹² The Mental Health Alignment Workgroup held community forums around the state that identified several problems in child mental health services:

- lack of local options for respite care, which can provide temporary help for parents struggling with a child's difficult behavior;
- too few child psychiatrists; and
- inadequate resources devoted to children's mental health.¹³

The Oregon Children's Plan, which is separate from OHP, targets all children ages 0-8 and their families, regardless of health insurance coverage. The plan seeks to reduce the risk of children developing health, mental health, substance abuse and other social problems. The state allocated additional funds in 2000 to expand early identification and treatment of mental disorders and substance abuse services available through the Children's Plan. Expanded services include in-home and school-linked services, parent-child attachment facilitation, behavior management training, preventive skill-building services for children, and other wraparound supports.¹⁴

MENTAL HEALTH SERVICES IN THE OREGON HEALTH PLAN

Like other states, Oregon covers a wide array of community mental health services under its Medicaid Clinic and Rehabilitation options. Medicaid-covered community mental health services for children in Oregon are as follows:

Outpatient Clinical Care

- Assessments
- Individual, family and group psychotherapy
- Crisis services
- Partial hospitalization
- Physician services, including medication management
- Prescription drugs

24-Hour Institutional Care

- Psychiatric hospital inpatient services
- Residential treatment center services
- Group home services

Rehabilitation Services:

- Intensive home-based services
- School-based day treatment
- Other day treatment
- Afterschool programs
- Family wraparound services
- Therapeutic nurseries
- Therapeutic foster care
- Therapeutic proctor care
- Individual psychosocial skills development

Case Management

- Targeted case management for children with serious mental disorders

BAZELON CENTER STUDY

In April 2002, The Bazelon Center held three focus groups of parents of children with mental disorders who are on Medicaid. One was held in Portland for parents in the urban area of Multnomah County, one in Salem attended largely by parents from the rural areas of Lane County and one in Grants Pass for parents from the six rural counties served by Jefferson Behavioral Health Care. Parents discussed experiences with their children with serious mental disorders on Medicaid, most of who were in the OHP. They also completed a short survey regarding their child's disorder and use of mental health services. For more information on focus group methodology, see Appendix A.

FOCUS GROUP PARTICIPANTS

Most participating parents were mothers (90%). The 46 children were primarily male (67%) and tended to be older; 46% were aged 7-12 and 35% were aged 13-18. Only 20% were 0-6 years old. Most children had multiple mental health problems, 94% of them having more than one diagnosis.

The diagnoses most often reported by the parents were:

- attention-deficit/hyperactivity disorder (ADHD) or attention deficit disorder (ADD), 65%;
- oppositional disorder/oppositional defiant disorder, 54%;
- learning disorder, 50%;
- depression, 45%; and
- post traumatic stress syndrome, 37%.

Most, but not all, children received their care from three MHOs: Verity, Lane Care and Jefferson Behavioral Health. Verity operates in Multnomah County, which includes Portland,

the state's largest city. Lane Care operates in Lane County in western Oregon. Jefferson Behavioral Health operates in six rural counties (Coos, Curry, Douglas, Jackson, Josephine and Klamath) in the southwestern part of the state, near the border with California.

Parents were asked in a written survey to indicate which plan their child was in or whether the child was open card. For those parents who failed to answer this question, the focus group they attended, e.g. "Portland Group" is cited.

More children were enrolled in Lane Care (16 children) and Jefferson Behavioral Health (12 children) than Verity (5 children) and open card (6 children). More than two thirds of children (68%) had been enrolled in their MHOs for more than a year. Since many mental health providers in Multnomah County do not accept Verity, parents in the Portland focus group were more likely to have opted out of the managed care program and selected the fee-for-service option. The children's race and ethnicity were slightly different from the state's as a whole: 83% were white, 7% African American, 4% Native American and 2% Latino. Except for age, there appeared to be no relationship between children's demographics and their experience with OHP.

FINDINGS

ACCESS, AVAILABILITY AND APPROPRIATENESS OF SERVICES

Parents generally found services available under Oregon's comprehensive child mental health services benefit to be helpful to their children — when they were able to obtain them. The state places a strong emphasis on early intervention for very young children and generally there is access to some level of basic outpatient treatment for children of all ages.

However, parents reported significant problems accessing many services when their children needed them, particularly more intensive community rehabilitation services. In fact, parents frequently found it hard to access any services at all for their child, enduring delays of many years before their child's needs were acknowledged. Parents said that, in the meantime, they were blamed for their child's disorder and their knowledge of their child's behaviors and problems was often discounted.

Parents were also unaware of the mental health benefits in the Oregon Health Plan, having received insufficient information from their plan, their county or the state. As a result, they did not know that certain important services needed by their children could be covered under the state's Medicaid plan.

Finally, parents reported that the lack of easy access and early intervention services— as well as the limitations on outpatient treatment and intensive rehabilitation services— has resulted in a crisis-oriented system where children deteriorate as families struggle to cope without adequate guidance or backup.

WHEN THEY HAVE ACCESS, FAMILIES FIND SERVICES HELPFUL

My child is on the Oregon Health Plan. I'm pretty pleased, actually, with the benefits. Because when she was on my private insurance before the SSI kicked in, she got nothing. (Lane Care)

Families reported that they found most services they received to be helpful. For some, the match of services to their child's needs was particularly appropriate. Often these children received several services in combination. Parents noted that several Medicaid services had been particularly helpful, including: early intervention, day treatment, intensive in-home services, case management, services provided by child psychiatrists, strength-based residential treatment, and family counseling and parenting skills training.

How well do I think the Oregon Health Plan is meeting his needs? I think pretty well right now for my youngest. (Salem Group)¹⁵

I think there's a lot of early intervention, which is a great thing. (Lane Care)

Most parents with younger children could obtain mental health assessments and services. In many cases, these children's problems had been identified at a very young age (0-3) when many significant mental disorders are typically overlooked. Identification of mental health issues in very young children in Head Start programs appeared to be particularly helpful to these families.

MOST FAMILIES HAVE LIMITED ACCESS

Not all parents were so fortunate. Parents whose children were older had, in contrast, often found it extremely difficult to obtain the mental health services their children needed. Either no services would be authorized or, when services were authorized, parents experienced long wait lists to receive services for their child from a limited selection of providers. Parents of adolescents were particularly concerned about the dearth of psychosocial skills training for youngsters to help them learn the necessary skills for independent living.

Families also believed that they had few choices, given the limited range of service options. They complained that MHOs did not individualize services based on their child's characteristics, needs or interests.

Some parents had fought hard to get their children the services they felt their children needed. These individuals were exceptional in their persistence and assertiveness, and are, unfortunately, unlikely to be typical of most Medicaid families. But for those who complained enough, services previously denied were suddenly found.

I know a lot of people that have children with severe emotional issues. You're thankful to get anything under the sun... you might not get anything else for two years. (Portland Group)

It's more of a snapshot of putting a child into what's already set, instead of looking at what they really need. And those services just don't matter. (Portland Group)

I had to beat on some heads for quite a while. It probably took me a good two years to get anybody to listen to me. I am a very persistent person. So, I had to beat on quite a few doors. (Jefferson Behavioral Health)

LACK OF ACCESS LEADS TO CRISIS-ORIENTED SYSTEM

Many parents expressed concerns that children with serious issues were not served until their condition progressed to an extreme. Before reaching such a level of severity, children with very serious problems typically received only basic outpatient treatment (medication and counseling).

And there just hasn't been a lot of support or recognition. It's like, if they're not starting fires or doing this, then okay. They're okay. (Grants Pass Group)

Parents found it easier to obtain services after their child had been hospitalized. Twenty-two percent of the families had received in-home services during the past year, but parents reported that these services were generally provided only after the child had been hospitalized, often multiple times.

My daughter had to do a lot of damage to herself before they could help her. (Portland Group)

Involvement with the juvenile justice system also increased access to more intensive mental health services. For some parents, follow up care upon discharge was poorly coordinated and the overloaded community systems were unable to respond in a timely manner.

I'm very happy with the services we're receiving now. My daughter is 13. But we weren't offered the services until she reached a crisis point and was hospitalized. That's when I really found out what was available. (Lane Care)

ASSESSMENTS ARE KEY, BUT HARD TO GET

Diagnosis was critical to being able to receive any services, and an accurate diagnosis was essential for accessing more intensive

[I would like to see] an accurate diagnosis; accurate and quick and clean. Because again, I think they try and keep it secret from you. Because then you might actually go get some help. (Salem Group)

And I saw it in him when he was about 13 months old for the first time. I thought that this is odd behavior. And by the time he was two, he had been booted out of five different day cares...The gap in identifying services for him and identifying a diagnosis and offering him adequate treatment was almost 10 years. (Lane Care)

I got on OHP about a year ago, and they pay for his medication fine... (Jefferson Behavioral Health Care)

But getting in to see a psychiatrist at Lane Care, which we are locked into in Eugene, is impossible. You get in and there's a three-month wait for an appointment. To get her meds re-evaluated another three months, and then in the meantime, she was off the deep end and out of her mind. (Lane Care)

services. Parents had experienced difficulties getting systems to recognize the severity of their child's disorder or to conduct appropriate, full evaluations to determine the diagnosis. Some went outside OHP to obtain an assessment and diagnosis on their own. Parents expressed concern that the lag in diagnosis resulted in children's entering the system only when they were in crisis.

Many parents reported a long gap, ranging from one to 15 years, between the time that they first knew that their child's behavioral problems were due to a mental disorder and when the system acknowledged that problem and diagnosed the disorder. During this period, parents typically saw their child's condition worsen.

Professionals in mental health and school systems who had ignored parental reports on children's behavior often were responsible for the delays, according to some focus group participants. For one Portland parent, the seriousness of her son's problems was simply ignored because her therapist did not believe her reports. Then her son began acting out in a therapy session for a younger sibling:

And it wasn't until probably a year after that I had one boy in a counselor, and I sat in at the time and had all the kids with me. And my oldest son was just being who he was, and talking in word salad. And the lady (therapist) shut the door and said, "You guys can't leave here." (The child had to be admitted to inpatient services immediately) And I said, "This is what it's been like for years." (Portland)

OUTPATIENT TREATMENT IS GENERALLY AVAILABLE

A substantial number of the children were receiving basic outpatient mental health treatment, including pharmaceuticals, medication management and counseling. For example, three quarters (74%) of children had received some counseling in the past year.

However, the shortage of psychiatrists was seen as a significant problem. Parents found that few were willing to accept OHP patients and those who did often were not accepting new patients. As a result, parents experienced months-long waits to get their children into services.

Parents also wanted counseling for their children more frequently. Parents say that they are limited to 8-12 visits a year, so sessions are spread out over a long period of time. It was not unusual for parents to report that their child received counseling

no more than twice a month, and often no more than once every 4-6 weeks. For children with serious mental disorders, providing therapy at such long intervals cannot be considered a therapeutically appropriate service.

Even for very young children, talk therapy was often the only service offered or available. Parents felt that their children with severe problems required different therapeutic approaches.

Some parents also felt that their counselors were inadequately trained. They felt that counselors changed too frequently to allow effective long-term counseling.

CRISIS SERVICES INADEQUATE FOR MOST

One third of the parents had needed to access crisis services for their children in the past year. Some had access to crisis residential placements and a few had access to mobile mental health crisis teams. Generally, however, parents found these services to be woefully inadequate, reporting that their MHO's crisis system consisted of a phone line to call for consultation with no backup face-to-face services.

Instead, parents would often be directed to go to the mental health clinic (during weekday business hours), to a hospital emergency room or to the police. Parents wanted access to 24 hour crisis services from trained mental health providers.

Some parents saw the police as the only option for crisis services, but families found that the police were not always prepared to handle children having a psychiatric crisis, and that interactions with the juvenile justice simply created a new set of problems for families (see Interagency Collaborations, page 18).

INTENSIVE COMMUNITY REHABILITATION SERVICES ARE SCARCE

Families generally did not have case managers, and when they did services were generally provided through the Office of Services to Children and Families or from the Office of Developmental Disabilities. Families felt that someone who could help them identify their child's needs, locate providers and advocate with service providers for their child would be very helpful.

Intensive in-home services were hard to get. Only 22 percent of the families received in-home services for their child, and they reported these services were generally only furnished for children who had been hospitalized, often multiple times.

I have found that [OHP] sets limit[s] on the amount of sessions that they can have yearly with a counselor. And they really need to be going at least once a week. It just doesn't work. (Grants Pass Group)

Individual counseling for a six-year-old child really didn't seem to do any good at all. (Jefferson Behavioral Health Care)

[I would like] a choice of counselors. When you're on OHP, you're limited. And say you don't like the counselors and the choices they give. Well, you're stuck. (Jefferson Behavioral Health Care)

If your kid needs the crisis center, it depends if the beds are available, too. I mean the kids are just going off the wall. If the beds aren't available, you're stuck with them. (Lane Care)

There were also times when we lived in an emergency room for a few days, waiting for a bed to open. (Open Card, Portland)

Nobody actually told us about them [case managers], we just fell into it. (Jefferson Behavioral Health Care)

My son is 8 years old. He is ADHD and a bit obsessive-compulsive... He went from Head Start into the day treatment program. He was there for probably close to a year and then went back into elementary school. And he's done really well and they were really competent with him. And OHP did cover that. The school that he's in is really wonderful and very supportive. (Jefferson Behavioral Health Care)

Their answer at the school, where our son's a statistic, was to bend his hand backwards and shut him in a closet. I took him out of school because I couldn't get anybody to listen to us. We talked to everybody. I went to everybody trying to get help. And nobody would help us. (Lane Care)

My nine-year old son was diagnosed a year ago with ADHD, and I was really worried about him, because he would threaten his sister with knives and threatened to kill himself and just went through a myriad of things. I actually received the most help in the beginning through his school. The assistant principal really likes him, and she helped me out quite a bit. (Jefferson Behavioral Health Care)

I believe that we're all here for the same reason: for our children – to make them succeed in society when we're no longer here for them. The only way is if they have social skills to deal with society. (Lane Care)

Day treatment services are also in short supply. This is true of both free-standing day treatment and school-based day treatment. Parents expressed frustration at having to wait months to years for placements in day treatment.

More than one third (39%) of the children had received mental health services, such as counseling, at their school during the past year. But many schools lack staff and programs to handle children with serious mental disorders. Usually, school counselors provided services and more intensive programming was typically not available in schools. School-based day treatment programs were too few to serve all children in need and in several areas of the state there were none at all.

Without services, children got into trouble at school and were removed from the classroom or administered some other form of punishment. Several of these children were unable to attend school.

A few parents were fortunate to find school personnel who were helpful or day treatment programs operated by schools.

Parents of older children expressed considerable concern that their plan offered few programs to help prepare their adolescents to function independently as adults. They wanted to see more psychiatric rehabilitation services to develop independent living and social skills.

Parents identified two services, respite and transitional services back to the community following inpatient and residential care, that they felt were extremely important and that they wanted to have added to the array of services covered under Medicaid. Parents felt that respite care would make a great deal of difference in their children's lives.

LONG WAITS FOR RESIDENTIAL TREATMENT

Many residential treatment centers have told parents they are not accepting children covered by OHP. Parents expressed frustration waiting from months to years for placements in residential treatment centers. Residential treatment center services for girls are particularly limited.

These waits caused families enormous difficulty as they struggled at home without the support and services they needed.

If I could get him into respite because it gets to you after three or four days of the banging-of-the-head stuff, and the big fits and stuff, you get to where you're stressed out and can't cope either. And you start yelling and that shoots your kid right off the deep end and they cut their throat. (Jefferson Behavioral Health Care)

I've had the benefit of a respite program that was in Klamath Falls County. And what that allows you to do is be able to take time out for yourself. Because what happens is people do not want to take care of children with mental health issues that are really high maintenance care for a price you can afford... And you've got to separate yourself from that child. And you've got to get out of that cycle, and you need to be able to make the break and take care of yourself. If you can't care for yourself, you are not any good to your family. (Jefferson Behavioral Health Care)

He's been recommended for residential psychiatric and nobody will take him. (Jefferson Behavioral Health Care)

[T]hey accepted him for residential. We had the interviews and everything and they said [there was] a two to four month waiting list. (Verity)

He was discharged in December. We had to wait from December to February for him to start day treatment. (Verity)

INTERAGENCY COLLABORATION

CHILDREN FALL BETWEEN THE CRACKS OF MULTIPLE AGENCIES

The lack of cooperation between OHP and schools, child welfare and other public agencies increased the difficulty of meeting children's needs. Parents felt that each agency expected the others to help their child, so no one provided assistance. Parents saw increasing communication and collaboration between all the public agencies involved with their child as a high priority.

One agency will see what's available, and they say, "We don't have to do that. Somebody else will take care of it." But then you get everybody thinking somebody else will do it. (Lane Care)

I come from California where interagency agreements were mandated by law. It was a huge difference coming to Oregon. (Lane Care)

He was hearing voices telling him to kill people and travel around with a knife. He was removed from my custody again in what they call a voluntary placement agreement... But it was not voluntary. I was told, "He will be on the streets and kill people, or you will give up custody and we'll get him treatment." I adopted my son. I traveled 3,000 miles to adopt that boy. So the issue of me giving up custody, I think was more sensitive for me than it might be for other parents. (Lane Care)

She was institutionalized this summer, and they required me to sign over custody to the State. That's something if your kid was awaiting a heart transplant they wouldn't require you to do, but since it was a mental illness, they made me relinquish her custody. (LaneCare)

CHILD WELFARE

Oregon state law allows families to enter into a "voluntary placement agreement" with the Offices for Services to Children and Families (SCF) in order to keep parents from being forced to give up custody to obtain services. When the only reason the family considers relinquishing custody is to gain access to mental health care — usually a foster home, group home or institutional setting — Oregon allows the child to enter the child welfare system but permits the family to retain their rights and obligations and to make key decisions about their child.

Children for whom there are voluntary placement agreements can be covered under Medicaid and the OHP. The law authorizing voluntary agreements is relatively new and was passed specifically to avoid parents being forced into giving up custody when there was no abuse or neglect.

Several parents appreciated the way that voluntary placement agreements served as an avenue to gain OHP coverage and provided their child priority access to limited services. However, several other parents had to strongly advocate with child welfare before the agency would open a voluntary case. Still others felt pressured into signing the voluntary agreement in order to obtain mental health services.

The major purpose of the Oregon law is often undermined. Many parents reported that the caseworkers at SCF treated parents who voluntarily relinquished custody no differently than parents who had to relinquish custody because of abuse or neglect.

JUVENILE JUSTICE

With the long waits for more intensive services, parents had found that the juvenile justice system can shorten the wait. Some mental health providers even recommended that parents call the police in order to get their child into that system.

Some parents found the juvenile justice system anything but helpful, cautioning other parents not to use that approach.

At least in Multnomah County, we've had to phone the police. And then the police still don't know what to do. (Verity)

It's been very, very frustrating, because the services just aren't there. And she ended up in detention so we could help her. She stole our car. We turned her in only because there was no other way to get her help. (Lane Care)

My son didn't really get any help until I had him arrested. You know, that put him into a whole different level; whole different category. I had to call the police on him and say that he hit me, which he did. But I kind of thought to myself when I woke up that day, "Okay. Today I'm going to let him hit me. We're going to play a game." (Lane Care)

And when my son was finally adjudicated and ended up in detention, where they said that he was awaiting treatment that wasn't available. They let me know there would be no treatment for him. But he is sentenced to be in detention in an eight-foot by ten-foot cell and can only come out in shackles and handcuffs very, very rarely. And I could only visit him twice a week for 30-minute intervals through a glass window. But he is not being punished. He was being held pending treatment. (Lane Care)

PROVIDER ISSUES

PARENTS ARE BLAMED

It wasn't until (he was) ten-and-a-half when the Ritalin started working. And the school, prior to diagnosis of that ADHD, kept saying, "What are you doing? What are you doing? What are you doing?" Now they're realizing there's something wrong with him, and it's not me. (Salem Group)

Parents reported with some bitterness that the first response of schools and mental health providers to their child's behavioral problems was to blame them as parents. Poor parenting skills or some type of abuse was often suspected. Even families who had adopted special needs children, who were expected to have behavioral problems due to premature birth or maternal substance abuse, reported that they were at first blamed for the child's difficulties. Parents saw OHP as unresponsive to their unique need for support and education as parents of children with serious emotional disturbances.

PARENTS TREATED DISRESPECTFULLY

There's also a stigma with the Oregon Health Plan; having that as coverage. (Verity)

They automatically assume you haven't got a brain in your head. (Open Card, Portland)

Many parents reported no problems with their providers and said they were treated with a similar degree of respect as other parents with commercial insurance. However, some, particularly in Portland, reported that mental health providers had treated them disrespectfully.

HEALTH PLAN ISSUES

INFORMATION FOR FAMILIES IS LACKING

Few parents really knew what they were entitled to under Oregon's Medicaid program. Most had not been informed by their child's MHO or by their providers about the full array of community mental health services available under OHP. A majority of parents were aware of coverage of basic outpatient services. For example, 81% were aware that therapy for their child was covered. However, parents were much less aware of coverage for intensive community services.

More than half of the parents surveyed did not know that eight of the 11 community-based mental health services for children listed in the state Medicaid plan were covered by OHP. More than half were unaware of OHP's coverage of intensive in-home services (57%), case management (57%), substance abuse treatment for children (59%), mental health programs separate from school (62%), and therapeutic foster care (62%). Even fewer parents were aware of Medicaid's coverage of therapeutic pre-school (16%) and mental health services at the child's school (13%). (See Table 2 in Appendix B.)

Parents reported that MHOs had not educated them on the services available under OHP. Most parents had never seen a list of mental health services. Members in only one of the behavioral health plans, Verity, reported that their member's handbook included such a list, but these families found the information difficult to understand. They complained that it was too long and was written in professional jargon. Parents with children enrolled in two of the MHOs (Lane Care and Jefferson Behavioral Health Care) had never seen a detailed service list in the membership handbook.

Providers also seemed poorly informed about the array of mental health services required by the MHO contracts. Parents recommended that the MHOs do more to educate providers on the available services.

Parents reported that they learned more about the availability of services from their own experience with the Medicaid program, other parents and family support groups run by the Oregon chapter of the National Alliance for the Mentally Ill. Parents were surprised to learn of the extent of the OHP mental health benefit package. When told of some of the services

I think I probably could have gotten a lot more services had I known about them. I could have advocated for them. (Open Card, Portland)

We haven't been given a guide. There's a few publications, but [not] a guide to what we are entitled to - services and the providers. We would like to see in writing what we are entitled to. (Lane Care)

I found out by word of mouth from other parents who have ... older children than mine and have been through and eventually found what they might be able to get. (Portland)

The staff at the Oregon Health Plan don't know what they cover. Everybody has a different answer sometimes. At the place that you go to, they may think a different thing than the people that you call at the insurance company. (Verity)

listed in OHP contracts, parents were amazed and angry that they had not known of them before.

FEW WERE AWARE OF FORMAL GRIEVANCE PROCEDURE

[Am I afraid of retaliation?] of course. I was told that I wouldn't get services. (Jefferson Behavioral Health Care)

Few parents were aware of their right to file a formal grievance. Some parents in Lane Care were incorrectly told that they could only file a grievance if they were refused any services at all, but not if they felt they had received an inadequate level of services. Many parents were afraid of filing grievances in areas with few providers.

PHYSICAL HEALTH NEEDS MORE EASILY ADDRESSED

They addressed anything physical quite easily. (Lane Care)

Parents reported it was much easier to find services for their children's physical health conditions than for their mental health disorders. Several parents of children with serious physical problems found that OHP did an excellent job addressing these issues.

CONCLUSIONS

DIFFERENCES BETWEEN PLANS

Generally, parents in all three sites expressed the same concerns, although there were some differences in degree of difficulty that families in each area were experiencing with their Medicaid program. However, a few specific problems were brought up in only one focus group. Since Oregon is a county-based system, it is not surprising that there should be some differences. Also, since solutions may be both state- and county-based, it is helpful to note the differences among the three groups of parents. These differences in degree of problems encountered, and the particular complaints in a specific focus groups are presented below.

LANE CARE

Parents in Lane Care appeared to have the greatest difficulty in finding the necessary array of mental health services for their children.

Counseling was more difficult to find in Lane Care than in any other health plan. Delays ranged from three to six months and parents found little choice of provider or type of therapy. Three month waits to see psychiatrists were typical for those in Lane Care and parents reported delays of up to a year for residential services. Parents were told by some Lane Care providers to let their child commit a crime, and then contact the police in order to get the child prioritized for mental health services.

Only a few parents in Lane Care received crisis services when they needed them. The Safe Center provided crisis services for children under the age of 13. White Bird, a mobile crisis unit, served children in the Eugene area. Most other families in Lane Care experienced great difficulties.

A small number of parents in Lane County School District said that their children had

benefited from appropriate day treatment programs such as the Child's Center.

VERITY

In Portland, Verity has been affected by Multnomah County's ongoing mental health crisis and has undergone numerous changes. A task force had been set up to develop a complete redesign of the mental health system to reduce inpatient psychiatric hospitalization and shift resources to step-down facilities and intensive community-based treatment. In terms of planning and resources, children's mental health services have received less attention than those for adults.¹⁶ The state's financial crisis in 2001 resulted in the closure of the Crisis Triage Center, a 24-hour psychiatric crisis center that served 9,000 patients in 2000.¹⁷

Parents of young children in Portland found that the Head Start Programs did a good job identifying mental health issues and referring their children to treatment. Children with repeated hospitalizations often received in-home services that parents saw as effective.

However, several Portland parents found that many psychiatrists have chosen not to contract with Verity. Some parents in Portland dealt with the lack of plan-affiliated psychiatrists by selecting an open card. Wait lists were long for appointments. Most parents also found the lack of after-hours crisis services to be problematic. In 2000, Portland's only mental health crisis center had closed. Parents in Portland now bring their children directly to a psychiatric hospital or an emergency room at a general hospital. Verity providers, like those in Lane County, had also recommended that parents try to obtain children's services through the juvenile justice system by letting their child commit a crime, and then contacting the police.

JEFFERSON BEHAVIORAL HEALTH

A small number of parents in the six rural counties served by Jefferson Behavioral Health reported that their children benefited from appropriate day treatment programs, such as the Klamath County schools and Family and Friends, a special school for children with attention deficit disorder. Several parents had positive experiences with residential programs.

However, Jefferson Behavioral Health providers had the longest waits (three to six

months) for psychiatrists. Faced with such delays, families in Jefferson Behavioral Health found it easier to make appointments instead with their child's pediatrician for psychiatric medication prescription and adjustment. Still, parents did not believe the pediatricians to be sufficiently knowledgeable about psychiatric medications for children, and expressed a strong desire to have their child be able to see a psychiatrist.

AREAS OF ACCOMPLISHMENT

The focus groups highlight the aspects of the Oregon child mental health system that are working the best. These include the following.

EARLY INTERVENTION FOR YOUNG CHILDREN

A number of parents in the focus groups were enthusiastic about the early identification of very young children. In particular, Oregon's Head Start programs appear to be doing an excellent job of identifying children's needs and helping parents to access services. Policies to support Head Start programs in this role could be beneficial to families.

SERVICES FOR GRADE SCHOOL-AGE CHILDREN

While access to services was anything but uniform across the focus groups and among the parents, a number of parents of children aged 6-12 reported receiving an array of appropriate services. Indeed, several of these families had case managers, received in-home services and

accessed services at school as well as basic medical and clinical treatment. When an appropriate set of interventions was provided, the parents felt strongly that services worked, and worked well, for children in this age group. This suggests that efforts to shift the system away from crisis management and toward more individualized care can be effective and yield substantial long-term benefits.

OUTPATIENT TREATMENT

While they did not find therapy as helpful as they felt it could be if it were available for longer periods of time and with shorter intervals between sessions, most parents in the focus groups were appreciative of their child's access to basic services, particularly medications and therapy.

CHALLENGES

In addition to suggesting areas where new policies might benefit children and families, these focus groups highlight some of the state's underlying difficulties as well as the strengths of the current system.

OREGON PROVIDER SHORTAGE

Many parents in the focus groups discussed the dearth of psychiatrists, psychologists and other mental health providers who can furnish mental health care. This is a greater problem in rural areas, but appears to present challenges in urban areas as well. The state could consider two strategies to deal with this issue: encourage providers to stay (or re-locate) in the state or work around the lack of professionals by increasing the number of para-professionals to support the limited number of professionals and expanding access to mental health treatment in primary care settings.

DIFFERENCES BETWEEN COUNTIES

As a county-based system, Oregon does not have a uniform mental health system. Differences in parent responses in the focus group highlight that there are far more significant problems in Lane County than in Coos, Curry, Douglas, Jackson, Josephine, and Klamath Counties. Major problems are also evident in Multnomah County.

Publication of data for Medicaid-eligible families and the public that compares county systems, particularly outcomes data, might help counties better assess their child mental health service systems and encourage those with weaker systems to develop policies to address these problems. While currently some data are released, its format is hard for the general public to appreciate, as it is designed primarily for policymakers.

POLICY RECOMMENDATIONS

These three focus groups have implications for Oregon's Medicaid program and suggest several areas where new policies, or greater attention to the implementation of existing policy, might greatly benefit families.

ADDRESS SERVICE INADEQUACIES

Oregon's child mental health services appear to be spread too thin in all three areas where focus groups were held. Most parents reported that their children either cannot get services or get extremely low levels of service. The existence of long gaps between therapy sessions also raises the question of how helpful those services can be. Children with serious mental disorders cannot be effectively treated with sessions so far apart that there can be no real continuity between one and the next. This, coupled with the scarcity of intensive services, such as day treatment and in-home services, has led to a system where children continually go into crisis (and eventually into residential programs) more often than should be necessary.

Such an approach simply mortgages the long-term viability of efforts to provide mental health services to children by shifting costs to the child welfare and juvenile justice systems. It also discourages the public, policymakers and staff of other systems from believing that mental health services can be effective (because at this low intensity they are not). Such a crisis in confidence can lead to fewer collaborations between agencies and fewer referrals to mental health services, exacerbating the downward spiral in access to needed services.

The state should seriously investigate the full impact of this approach. The strategy may help realize cost savings in the short term, but ultimately comes at a tremendous cost to Oregon's children with mental disorders.

INDIVIDUALIZE SERVICES

Parents are frustrated by the cookie-cutter approach of most MHOs, and feel their children would do better if there were more individualized care. Individualized services are a primary principle of a strong child mental health system, as articulated by the Center for Mental Health Services through the Child and Adolescent Service System (CASSP) System of Care Principles. Adoption of such an approach by all MHOs would greatly assist parents.

DEVELOP AND PROVIDE A RANGE OF APPROPRIATE SERVICES FOR OLDER CHILDREN

Across all systems, adolescents are having the hardest time accessing services that are appropriate for their needs. As children get older (and grow in size) parents have greater difficulty coping at home with worsening symptoms of mental disorders. Year-round structured day services and services relevant to adolescents (such as daily living skills and other psychosocial rehabilitation) can be covered under Medicaid. However, the Oregon Health Plan is not making such services available to the youth in focus group families.

IMPROVE CRISIS SERVICES

Crisis services within the mental health system were largely unavailable to parents in the focus groups. Reliance on general health emergency rooms or other health care providers may seem a feasible approach, but it does not appear to result in those systems' being open to children in a mental health crisis or to their responding appropriately. A better option is the mental health mobile crisis teams that exist in some areas. More mental health crisis teams are needed to go to the children's homes or other community settings to defuse crisis situations and to arrange appropriate and prompt follow

up treatment. If this is not feasible, increased collaboration with other health systems is needed to improve their responses to children with psychiatric crises.

PROVIDE MORE INFORMATION TO PARENTS

Parents were often unaware of their benefits under OHP. Federal regulations require that states ensure that managed care enrollees have information on benefits made available to them in easily understandable format. The state is responsible for meeting this requirement. Since OHP plans are failing to fulfill this mandate, the state should consider developing a short, simple brochure for families to explain the child mental health services under OHP and distributing the publication widely so that all families of Medicaid enrolled children have the information they need and are entitled to receive.

LISTEN TO PARENTS

Parents in these focus groups reported that systems were slow to recognize the reality of their child's disorder. A majority of the parents had initially been blamed for their child's problems and denied services. Gaps of between one and 15 years between when the parent knew their child had a significant problem and when a service system acknowledged and responded to that need are extremely detrimental and should be reduced. Training is needed for school personnel, child welfare workers and all OHP providers on how to recognize significant mental disorders in children and how to partner with families to address child mental health problems.

IMPROVE INTERAGENCY COLLABORATION

The three other significant child serving systems — schools, child welfare and juvenile justice — are not providing parents in these focus groups with needed services and supports.

- Too few schools recognize the problems these children have and far too few intensive day services are available in schools.

- Child welfare voluntary custody agreements are not working. Families either feel the voluntary agreement they enter into takes away their rights, even though it is not intended to, or they are actually pressured into giving up custody by child welfare workers. Parents with voluntary custody agreements also find they are treated no differently than parents who lose custody due to abuse or neglect.

- Juvenile justice systems approach these children with a punitive approach. Parents with experience in this system vehemently urge other parents to keep their children out at all costs.

These problems arise in all states when the four core child-serving agencies are not working together, with a common set of objectives, a common understanding of what these children need and a collaborative approach that makes the most efficient use of the special skills and the resources from each system. Child mental health systems generally have the fewest resources but the greatest expertise to offer. Without collaboration, children and families face not only uncoordinated services, but service systems that work against each other's objectives.

High-level collaboration across all systems is needed to initiate stronger collaborations at the local level. More attention to how other systems handle children with mental health needs would benefit families and children significantly.

APPENDIX A: FOCUS GROUP METHODOLOGY

Each of the focus groups was approximately two hours. Participants also completed a short survey about their children and their children's use of mental health services. As is standard focus group policy, participants were paid for their time. Since these are parents of children who need ongoing supervision, childcare was also made available.

Participants were recruited through the Oregon Family Support Network (OFSN). OFSN, a chapter of the Federation of Families for Children's Mental Health, has supported families that have children with emotional, behavioral, mental and related disorders since 1992. The organization offers tips on working with insurance or welfare systems, support in finding solutions for children and information on children with special needs, special education rights and laws. OFSN placed an announcement in its winter newsletter that directed family members to call its 1-800 number. The statewide volunteer coordinator screened families for their children's Medicaid eligibility and diagnosis with a serious emotional disturbance. Due to the difficulty of locating parents of children with serious emotional disturbance, random selection was not feasible. All interested families were invited to participate.

The focus group followed the guidelines described by Richard Krueger in *Focus Groups: Second Edition: A Practical Guide for Applied Research*, 1994 by Sage Publications. The focus group topic guide was developed by the Bazelon Center with input from the staff at OFSN and the Bazelon Center's Institutional Review Board (IRB). The short survey, topic guide, consent form and research protocol were reviewed and approved by the Bazelon Center's IRB in January 2002. A stenographer transcribed each of the focus group discussions.

Families of children with serious emotional disturbance who qualified for the Oregon Health Plan were targeted for recruitment. Nevertheless, a small number of families with children who were never enrolled or not enrolled in Medicaid during the past six months attended the focus groups. Children not on Medicaid have been removed from the short background survey totals and their parent's quotes are not included in the report. Their responses could not be removed from data on the family awareness of services which was collected during the discussion.

The findings of the focus groups are affected by the use of a nonrandom sampling technique and also the selection of 8 counties for study in a county-based system. Multnomah County, the most populous county was selected. Two other counties that are seen as in the middle of performance were also selected.

APPENDIX B: DATA TABLES

**Table 1: Percent of Children Receiving One or More Unit of Services
Through Oregon Health Plan
2002**

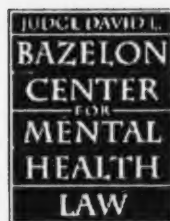
SERVICE	PERCENT OF CHILDREN
Therapy for Child	74%
Therapy for Family	57%
Family Support	54%
Crises Services	33%
Mental Health Services at Child's School (during or after)	39%
Intensive In-home Services	22%
Mental Health Programs Separate from School (such as day treatment)	22%
Substance Abuse Treatment	11%
Therapeutic Foster Care	13%
Therapeutic Preschool	2%
Other Mental Health Services	26%

Table 2: Family Awareness of Mental Health Services, 2002

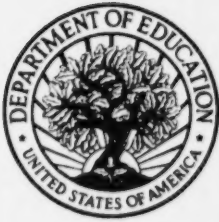
SERVICE	PERCENT OF FAMILIES
<i>Services known by 76% - 100% of families</i>	
Therapy for Child	81%
Crisis Services	73%
Family Support	70%
<i>Services known by 25% - 40% of families</i>	
Intensive In-home Services	43%
Case Management services	43%
Substance abuse treatment for child	41%
Mental health programs separate from school (such as day treatment)	38%
Therapeutic Foster Care	38%
<i>Services known by 0% - 24% of families</i>	
Therapy for family	24%
Therapeutic pre-school	16%
Mental health services at child's school (during or after school)	13%

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